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For an interview with Joni Aldrich or a review copy of one of her books, please contact Dottie DeHart, DeHart & Company Public Relations, at (828) 325-4966 or DSDeHart@aol.com.

“I Don’t Believe You Just Said That!”

Eight Statements to Question in Your Cancer Fight

It’s common knowledge that the expression “sticks and stones may break my bones, but words can never harm me” is just not true. And when you’re fighting for your life against cancer, words can actually make all of the difference in the world.

Winston-Salem, NC (May 2010)—Words are very powerful. We speak 16,000 or so of them every day, and, inevitably, some would have been better left unsaid. While words may not inflict material damage, their ramifications *can* be life-changing—especially when they or their timing affect your safety and well-being during a cancer battle.

Author Joni Aldrich knows about the subject of cancer—and its ramifications—all too well. In 2006, she lost her 43-year-old husband, Gordon, after a two-year battle with the disease, partially as a result of trusting the wrong medical treatment facility and team for the first five months of the fight to save Gordon’s life. Aldrich’s first book, *The Saving of Gordon: Lifelines to W-I-N Against Cancer* (Cancer Lifeline Publications, 2009, ISBN: 978-1-4392550-3-2, \$19.95, www.thecancerlifeline.com), tells the story of the Aldrich family’s experiences while simultaneously offering valuable step-by-step advice that will give readers the tools they need to have a fighting chance against cancer.

For Aldrich, the first “I don’t believe you just said that!” moment came during the initial visit to Gordon’s oncologist. The couple had done their research and had found a highly-qualified research facility for his type of cancer that was based in Little Rock, Arkansas. When they asked the doctor about a referral, he said, “I’ve never seen anything good come out of Little Rock, Arkansas!”

Unfortunately, the Aldriches didn’t challenge the doctor’s decision. And as a result, the second “I don’t believe you just said that!” statement surfaced five months later. The same oncologist called Aldrich at work and told her that her husband’s cancer treatment was now a “salvage operation.” That news was enough to send the couple racing to the Multiple Myeloma Institute in Little Rock, regardless of the oncologist’s opinion. By then, though, too much damage had been done by wasted treatments and time. Within a week, Gordon had to be admitted to the hospital—the pain was too severe from the 200 tumors that were eating his bones from the inside out. While the facility in Little Rock did help Gordon, the cancer had taken a firm hold in his body. After three stem cell transplants—which produced only three months of

remission—the cancer finally won.

So, what statements should you take at face value, and when should you persist in digging deeper? Here are a few of those “I don’t believe you just said that!” statements to watch out for. And be aware: they’re not always from a doctor.

The End-of-the-Road Sucker-Punch. *“Mr. Smith, I’m afraid there’s nothing we can do about your cancer. It would be best to put your affairs in order.”* Sometimes these words are accurate...and sometimes, that’s not necessarily the case. Aldrich brings up several points to keep in mind if this is what you’ve been told:

1) Before you go for your first visit with your *first* oncologist (*not necessarily your primary oncologist*), it might help to realize that this is just your first *opinion*. Webster’s definition of an opinion is a “belief stronger than impression and less strong than positive knowledge.” At no point should you settle for betting your life on one opinion!

2) Cancer physicians now tend to stay away from predicting the date of your demise. (Where is that expiration date stamped, anyway?) In broad terms, physicians *can* give you the average survival rate based on facts that they should know. They should also be able to tell you whom and where your type of cancer’s “experts” are. They can even set up that referral for your second *opinion*. If you need help with this, you can call the American Cancer Society and ask to be directed to the annual caseload by cancer type on the ACS webpage. This information is also in *The Saving of Gordon*.

3) While Aldrich doesn’t want to offer false hope, she points out that there is sometimes a ray of hope to cling to. “So many people I talk to either have heard these words firsthand, or have had family members to receive this ‘verdict,’” she recalls. “Some of those people are still walking around—it just wasn’t their time. While there has to be a fine line between treating for the patient to survive and treating a patient when there is truly no possibility of recovery, there is always continuing research. Ask about clinical trials that might be available for your type of cancer. Reach for that star if you feel you can. While the personal choice of the patient should always be considered in any cancer decision-making process, there are no simple answers surrounding a cancer diagnosis. And every single cancer treatment facility treats each cancer a little (or a lot) differently.”

The Heroic Lone Ranger. *“Honey, there’s no need to go to the oncologist with me today. I’m just going for a check-up.”* Wrong. Tag teaming it (taking back-up with you to every oncologist’s visit) is very important. Cancer is complicated. It’s an unfortunate fact that you never know what may come out of a visit to your oncologist. Decisions come in multiples and sometimes have to be made quickly. In these situations, two sets of eyes and ears are better than one set, especially if the patient isn’t feeling well. Ask for and listen carefully to all of your options.

“The goal is to stretch your oncologists’ capabilities,” explains Aldrich. “There may be many things that he or she hasn’t thought of in regard to your treatments. There are many twists and turns in the cancer road. During one fateful visit to Gordon’s oncologist, we were told that his

cancer had metastasized to his spinal fluid. I had driven ten hours the day before to be with Gordon. Had I not been there, I would have been left scrambling to catch up with what was going on. And things were accelerating at an astounding pace. There's usually no time for a 'do over.'"

The Most-Likely-to-Succeed Proclamation. *"This is the best cancer treatment center and oncologist in this area to treat your type and stage of cancer."* Maybe; maybe not. According to Aldrich, the key words in this statement are "in this area."

"Cancer isn't a popularity contest. Nor is every cancer treatment facility or oncologist created equal," she insists. "Would you want to get treatment at a facility that treats only 50 patients with your type of cancer every year, or 350? The statistics may be surprising, and assumptions can be deadly. While it's nice to have a doctor you like, I think we'd all agree that one who can save your life is more important. Honestly, oncologists expect patients and their families to be an active part of all cancer treatment decisions. It's helpful to realize that they are just human beings, too. As much as we want to believe that they have God-like powers, you should realize that isn't the case."

The Blind Follower. *"I'm afraid to ask questions. The medical professionals are the experts. They will keep me informed and explain what needs to be explained."* Maybe, but you still need to know the basics. Prepare your own questions before going to the oncologist, but don't limit your questions to those you've prepared.

"The only stupid questions are the ones that you don't ask," reminds Aldrich. "You have a right to know what's going on, and, be aware, there will be an incredible amount of details. Cancer medical professionals have lots and lots of patients of which you are only one, so *you* are the most qualified to focus on your treatment. If you hear something you don't understand, stick with it until you do understand it."

The author's second book (companion to her first book, *The Saving of Gordon*) is designed to help cancer patients and their families stay organized at every oncology visit. *The Cancer Patient W-I-N Book: Our Cancer Fight Journal* is available at bookstores nationwide and from major online booksellers. It includes everything you need for recording 33 oncologists' visits.

The Patronizing Pat on the Head. *"Mrs. Smith, it isn't important for you to get copies of all medical test results. That's my job. I'll keep you informed, and reading the results may alarm you unnecessarily."* Maybe; maybe not. Insist on printed copies of all medical test results. You're entitled to them, even if you use them to line the trashcan. Yes, many documents contain a lot of medical mumbo jumbo—but if you stick with it, you'll start to understand the basics. You and your insurance company paid for those results, and you have a right to receive them. If a physician or treatment center asks you why, simply say that you want to keep them in a file to document your progress. Period.

"So, why exactly is it important to have copies of your test results?" Aldrich asks. "During one of Gordon's first surgeries, a bone marrow biopsy was performed, but the results were never shared with us. Consequently, we were unaware that Gordon's cancer was more aggressive than

most cases of his type of cancer. We were literally at another cancer treatment facility when we found out about those test results. I was livid, because we wasted precious time and it may have shortened Gordon's life. When I say 'the devil's in the details,' I mean it. You *need* the details."

The Benevolently Neglectful Spouse. *"It's not important for me to understand every treatment that my spouse receives. As long as the chemotherapy nurses know, I can always ask them."* Not true. Don't limit your "questioning" to just oncologists. Cancer patients and their caregivers have to be aware and alert at all visits to cancer treatment centers. Even the best medical professionals at the best cancer treatment facilities can make missteps—and even outright mistakes—that can be costly.

"During my husband's third stem cell transplant, one of my jobs was to give him around-the-clock IVs of nutrients that the chemotherapy had stripped out of his body," Aldrich recalls. "As I was leaving the hospital one day with a grocery bag of baby bottle-like infusions, one of the nurses thought to mention that I wasn't to give two of the same type of infusions through both of Gordon's ports at the same time, or he could have a heart attack. I had been giving him those IVs through two other transplants, and that subject had never come up. If there's ever any question or if you don't feel comfortable with something—it's okay to insist on and expect better information."

The No-Big-Deal Brush-Off. *"I don't need to go in with my spouse for this. They're just giving him a shot."* If your spouse were having a routine physical performed, this statement would be reasonable. But that's not necessarily true with cancer patients, because with them, a shot is not always just a shot. We all go to doctors and get injections of different types, and sometimes there are bad reactions—even allergic reactions. Cancer patients take so many medications that there is always a possibility that something might go wrong. The patient and caregiver should understand all medications that are administered to the patient—even if it's only a shot.

"After Gordon's second round of melphalan chemotherapy (a derivative of mustard gas), he woke me up in the middle of the night saying that he didn't feel well," Aldrich shares. "When I took his blood pressure and pulse, they were off the charts. I knew that Gordon was having a bad reaction. After I rushed him to the hospital, he was admitted and stabilized. It could have been much worse if I hadn't been aware and alert. As the caregiver, you are the front line of defense in any situation. Whether the shot is chemotherapy or a blood cell booster, each one matters."

The Urgent Ultimatum. *"Mrs. Smith, we need to perform a radical mastectomy right away. There is no time for a second opinion."* Even if you hear these words, weigh your options carefully.

"In *The Saving of Gordon*, I relate the story of a friend of mine who—after being diagnosed with breast cancer—received a message on her answering machine that her oncologist (her *first* oncologist!) had already scheduled a radical mastectomy for her," recounts Aldrich. "Aside from the fact that she and her husband were shocked to receive that message so casually, they knew her breast cancer was Stage I. They immediately scheduled an appointment with another oncologist for a second opinion—a good move, because she had a lumpectomy instead, and today (years later) is still cancer-free. Thank goodness my friend didn't blindly trust her first

oncologist, because there can be serious side effects of radical mastectomies (such as lymphedema), especially if the patient can do without one.

“Hitting even closer to home, I now know that one of Gordon’s surgeries—a very painful procedure—should have been questioned. He always believed that we had made the wrong choice in going ahead based on one surgeon’s advice, because it hampered his recovery from his stem cell transplants. Since then, my hackles immediately rise when I hear someone say, ‘There is no time for a second opinion,’ or, ‘I trust this oncologist, and he comes highly recommended.’ While I’m not questioning the physician’s expertise, I also know that surgery is serious—no matter what it’s for. There is no such thing as a simple operation. Weigh your options carefully.”

“Ultimately, when it comes to cancer—or any medical condition, for that matter—the rule of thumb is to never let a statement, verdict, or recommendation slide by without first examining it fully,” Aldrich concludes. “If you have doubts, voice them. If you have questions, ask them. And if you want more explanation, don’t leave until you get it. In the end, your persistence might literally save your life.”

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About the Author:

Joni James Aldrich believes that she has been preparing to write *The Saving of Gordon* and *The Losing of Gordon* for most of her life. As a child, she was a better than average student. She wrote dramatic poetry. Before college, she worked at a newspaper. In her professional career, she has worked in analysis, documentation, communications, and public speaking. She has also been able to incorporate her love of photography into the design of her books. However, her real motivation for writing *The Saving of Gordon* was two years of crisis in the cancer school of hard knocks. She feels it is her destiny to relay this story to readers in a way that will help them in their own cancer journeys. It is her hope that someday that journey will no longer be necessary for anyone.

Joni is also the author of *The Cancer Patient W-I-N Book: Our Cancer Fight Journal*.

For more information, please visit www.thecancerlifeline.com and www.griefbeacon.com.

About the Books:

The Saving of Gordon: Lifelines to W-I-N Against Cancer (Cancer Lifeline Publications, 2009, ISBN: 978-1-4392550-3-2, \$19.95) and *The Losing of Gordon: A Beacon Through the Storm Called “Grief”* (Cancer Lifeline Publications, 2009, ISBN: 978-1-4392649-3-5, \$15.95) are available at bookstores nationwide and from major online booksellers.